2014

# Perceptions of Health Information on General and Medical Social Media Sites

Brea Hope Rich
*University of Mississippi. Sally McDonnell Barksdale Honors College*

# PERCEPTIONS OF HEALTH INFORMATION ON GENERAL AND MEDICAL SOCIAL MEDIA SITES

by
Brea Hope Rich

A thesis submitted to the faculty of The University of Mississippi in partial fulfillment of the requirements of the Sally McDonnell Barksdale Honors College.

Oxford
May 2014

Approved by

_____
Advisor: Dr. Donna West-Strum

_____
Reader: Dr. Erin Holmes

_____
Reader: Dr. Matthew Strum

## DEDICATION

This thesis is dedicated to my mother, Joy Rich. I would not be where I am today without the values she and my late father instilled in me. I am thankful for the example that my parents set for me, and I know that I would not be in pharmacy school or graduating from the Honors College without their love, prayers, and encouragement along the way. With each educational accomplishment, my mother has taught and continually reminded me of what is truly important in life, and for that, I am grateful.

ACKNOWLEDGEMENTS

I would first like to express my sincere gratitude to my thesis advisor, Dr. Donna West-Strum, who has played a large role in my life since she became my career mentor through the Ole Miss Women's Council. I am thankful for her willingness to also become my thesis advisor and for her guidance and encouragement along the way. She has made working on this thesis more enjoyable than I thought possible, and it has truly been an honor and joy to work with her over the past few years. I also want to thank South Tippah School District Superintendent Frank Campbell for sending out my survey and being so willing to help me with my research in any way possible. Thank you, South Tippah School District employees, for participating in my survey and encouraging my success throughout my high school and college careers. I also could not write these acknowledgements without thanking my sister and best friend, Bekka, for the continual prayers and love she has given me. I am thankful for such a great role model by my side for the past 21 years. Lastly, I thank God for giving me the ability to study and learn and the opportunity to be a part of this great university. I hope to use the talents he has given me to glorify Him with my life and career. I would not be who or where I am today without His grace toward me, and He has given me more than I could ever deserve.

ABSTRACT

BREA HOPE RICH: Perceptions of Health Information on General and Medical Social Media Sites

(Under the direction of Dr. Donna West-Strum)

The goal of this thesis is to identify and discuss the public's perception on health information found on general and medical social media sites. To discover this information, a survey was sent to employees of South Tippah School District. It was found that people are more likely to use general social media sites compared to medical social media sites. People are more likely to share medical information than receive information on either type of site. Most people doubt or are uncertain of the credibility of health information on social media sites. The benefit found most in reading or sharing medical information on social media sites is increased social support. Medical social media users greatly support the idea of health care provider monitoring on these sites. This information is useful to pharmacists as they realize that each patient they are encountering could very likely have knowledge gained from peers on a social media sites. Pharmacists should also be aware of the study's findings as they consider creating their own social media sites for their pharmacies.

TABLE OF CONTENTS

LIST OF TABLES

## INTRODUCTION

### Purpose

The purpose of this study is to describe the general public's perception on using and sharing health information on both general and medical social media sites. The study objectives are to describe people's attitudes toward using and sharing health information on social media sites, perceived credibility of the health information on social media sites, the perceived benefits of using social media for health purposes, and the perceived need for monitoring with respect to health information on social media sites.

### Background

Although a specific definition for social networking sites is difficult to articulate, Nicole B. Ellison defines them as "web-based services" that allow users to create a "public or semi-public profile," create a list of other site users with similar interests, and view their own list of connections as well as connections made by others. Based on this definition, the first social network site that appeared was SixDegrees.com in 1997. This site was created to help build connections between people, and it was the first site to combine the features of personal profiles, friend lists, and access to others' friend lists. The site attracted many users initially, but it came to an end in 2000, as it was said to be

"ahead of its time" since most people did not have extended networks of friends online. Various social networking sites launched over the next several years, focusing on specific demographics and holding specific purposes like finding a perfect date. The next big break was in 2003 when MySpace was born. The site went a step further by connecting bands and celebrities with their fans and allowing profile personalization. The site even allowed minors to join, which created an influx of teenage members, connecting with their friends, families, and favorite bands. Facebook began in 2004 as a Harvard-only social networking site and soon expanded to all others with university e-mail addresses. In September 2005, the site expanded again to allow high school students to join, and eventually, everyone was allowed to join. The features that set Facebook apart at this time were the inability of public viewing of full profiles and the ability of outside developers to create "Applications" that allowed users to do various tasks on Facebook. Although broad social networking sites like Facebook are most common, sites reaching out to specific groups also thrive on the web, from activity-centered sites to affiliation-centered sites. It is quite difficult to put a number on how many people use social networking sites today, but marketing research clearly indicates that the sites are growing in popularity worldwide. (Ellison, 2007)

UGC (user-generated content) via social media is becoming more and more prevalent in today's society. UGC on these websites is defined as "media content created or produced by the general public rather than by paid professionals and primarily distributed on the internet" (Daugherty et al., 2008). Erik Qualman, the author of *Socialnomics,* describes this phenomenon by saying, "Social media isn't a fad, it's a fundamental shift in the way we communicate" (O'Brien, 2011). The average person is

constantly bombarded with information from friends and businesses on sites meant for connecting and socializing. Websites such as Twitter, Facebook, and YouTube are even used for product advertisements and opinions. Because of this, the consumer is gaining a sense of empowerment in the marketplace. This empowerment results from learning from current customers, prospective customers, and critics in all walks of life.

When looking at the reasons people contribute to social media, Daugherty et al. (2008) narrowed it down to three motivations: (1) self importance and self esteem, (2) agreement with content in terms of their own moral beliefs, and (3) the act of forming friendships and belonging to a community. His study found the ego explanation to be the most compelling motivation for user participation on social media.

When thinking about users sharing information about various products online, one is led to wonder if users also share information about their medical conditions and treatments. According to Alexa, which is "the leading provider of free, global web metrics" that ranks around 30 million websites around the world, the two most prominent social networking sites are Facebook and Twitter ("Site Info"). In addition, YouTube is found to be the third overall most visited site on the web.

It is becoming evident that Facebook, Twitter, and YouTube are used by patients to share personal medical information. An article in the Atlanta Journal-Constitution entitled "Medicine in the Facebook Age" shares the story of a 56-year-old woman with very little family contacts who came into a hospital and soon lapsed into a coma. Her "diary-like postings on Facebook" were used to get a complete and detailed account of her health information that could not be received from the woman herself or any close

family members. She posted about her medications, symptoms, conditions, and trips to the hospital, and these pieces of information ended up saving her life as the physicians pieced together the things that had caused her heart problems and resulting coma.

In Alice Park's article "Web MDs," it is also seen that social media can be useful in the "crowd-sourcing" it can allow. By posting his wife's medical history, previous test results, and current updates on a Facebook page, Simon Turkalj could have saved his wife's life. He says, "Yeah, you can get wacky answers, but the high-quality responses make it all worthwhile." This article also shares several stories of people from the general public posting their symptoms on a social media or blog site and receiving a possible diagnosis from other Internet users, often from around the world.

While all three of these popular social networking sites are used to some degree for medical advice, there are also social networking sites specifically intended as support groups for patients with conditions or diseases. Two of the most popular sites, according to Alexa, are HealthBoards and PatientsLikeMe. According to the audience demographics for these websites, it seems that the majority of the viewer population is female and between the ages of 18 and 34.

One point of the disclaimer on HealthBoards clearly states, "the message boards are for entertainment, sharing and for peer support purposes only. Information included in a message board should not replace necessary medical consultations with a qualified health professional to meet your individual health or medical needs, or those of your loved ones." (HealthBoards.com FAQ, accessed 2 March 2013). PatientsLikeMe has a similar warning: "All of the material provided on the site, such as text, treatments,

dosages, outcomes, charts, patient profiles, graphics, photographs, images, advice, messages, forum postings, and any other material provided on the site are for informational purposes only and are not a substitute for professional medical advice or treatment." (Patientslikeme.com User Agreement, accessed 2 March 2013).

Upon joining PatientsLikeMe, a participant enters many pieces of data that are compiled to create a healthy history profile for that person. The main aspect of the profile is a summary of the person's current status, which includes a small diagram of a person with affected areas of the body highlighted and various charts that measure things like the rate of progression of the condition, the dosages of medications taken and the purpose of each, and the severity of symptoms associated with the illness. Upon making a profile, a user can use the searching and browsing tools to find other patients in a similar medical situation. He or she can discuss with this person through private messaging, public forums, or comments on each other's profiles. Each contribution to any of these communication tools includes a small snapshot of the posting user's medical summary. In the "Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data" study, there were found to be three main categories of comments on the questions: "(1) targeted questions to others with relevant experience, (2) advice and recommendations, and (3) forming and solidifying relationships based on similarity."

In a study researching outcomes on the PatientsLikeMe website, it was found that a vast majority of users considered the information they gained from PatientsLikeMe as "moderately helpful" or "very helpful." These patients use the site mostly for learning about their particular symptoms and understanding the side effects they are experiencing

because of their medications. Both of these benefits were obtained from finding another patient who was experiencing the same medical condition as themselves. As expected, this website could give the patient a desire to start taking a new medication to treat a health problem, to switch medications after they had already been prescribed a medication, to change the dosage of their prescribed medicine, or to stop a current medication. Of these four alternatives, the most often seen is the desire to begin taking a medicine after seeing another user's post about a positive experience with that particular medicine. This study also showed that the more of the previously mentioned features of the site that are used, the more benefit a participant receives from the site. (Wicks et al., 2010).

It must be remembered that on average, a physician can only speak with a patient with a chronic illness 15 minutes on average per visit, often using medical jargon that the patient cannot even fully understand (Wicks et al., 2010). Because of this, many people in minority groups or with low socioeconomic status fail to visit a physician when necessary and often take medications without permission from a physician. The Internet provides a way for these patients to find answers to their medical questions without directly speaking to a physician and the opportunity to join a supportive community that can relate to the problems they are experiencing. This allows the patient to assume more responsibility over their medical care and reduce their reliance on the healthcare system.

Seventy-four percent of American adults have access to the Internet, and sixty-one percent uses the Internet to find medical advice (Wicks et al., 2010). It seems that these adults, including the elderly ones, are very open to the idea of having the option to e-mail their physicians, but for some reason, only around seven percent of physicians

utilize e-mail conversations with their patients. This explains the growth of medical social media sites.

However, less than 15% of people actually post information on social media sites. Therefore, people are much more likely to refer to social media for medical knowledge than they are to post their own medical knowledge or experiences. The groups of people that are more likely to use social media sites for health information are people that are in young age groups and have a regular health care provider and a chronic disease (Thackeray, 2013).

Although changes in the medical outcomes of social media users are difficult to study, there have been patient benefits observed. An example of this is seen in HIV patients on PatientsLikeMe. A tool exists on the site that can help a patient understand his or her lab values from CD4 and viral load tests. This tool helps patients to understand the importance of taking medications consistently. In fact, 41% of HIV patients reported that they had lowered their risky behaviors after viewing the site, and 29% even decided to take antiretroviral drugs. Also, psychological and emotional improvements have been seen. Patients have a heightened perceived control over their illnesses, a greater medical knowledge, and a personal empowered feeling.

The above outcomes are beneficial, but physicians worry that these social media sites could be causing more harm than good. This results from the fact that many patients are able to easily diagnose themselves using information that is found online, much of which could be incorrect or misleading. However, only 3% of patients using medical information sites have admitted that they or someone they personally know has been

harmed by following the advice or health information found online (Sharing Health Data). According to a study entitled, "Analysis of Cases of Harm Associated With Use of Health Information on the Internet," only one report was found of unintentional physical harm to a human. This report involved a middle-aged man who found a hydrazine sulfate remedy for his sinus cancer. He treated himself for four months and subsequently had hepatorenal failure that resulted in his death (Crocco, 2002).

In the 2001 journal article entitled "Review Of Internet Health Information Quality Initiatives," the issues that affect the quality of online health information are explored. It seems that the only way that online health information sites would be successful and helpful is if the patient is educated and interested, the site meets a set of quality criteria, and a type of instrument is designed to test credibility. It seems that even when health information online appears to be of a high quality, it can still cause harm to its viewers. Reasons for the unintentional harm include language barriers, an audience that is not matched correctly to the information given, the inability of a patient to interpret data, the accuracy and timeliness of the information, and the partiality of the source itself. However, it seems as if many online patients are against the idea of having governed health information. The main reasons, none of which are "compelling" according to this article, include the viewer's indifference and ignorance and his or her right to free speech. The author of this article thinks it is imperative to address this issue because of the great harm that online health information can bring to citizens. He ends the article by addressing the World Health Organization (WHO) and suggesting ways to solve the problem by developing standards for the quality of online health information (Risk, 2001).

With a growing number of people using social media, it is important to understand how people are using it for medical advice. This study will provide insight into the general public's usage of social media, view on health information credibility on these sites, opinions on the benefits of these sites, and thoughts on implementing a type of monitoring within these sites.

## METHOLOGY

### Sample

Employees of South Tippah School District during the 2013-2014 school year were the population studied. The Superintendent of Education of this school district distributed the survey (Appendix A) via e-mail to all employees. Only one school district was surveyed due to the limited resources of this study. The population included teachers, administrators, and other employees of the school district. This group was chosen because it is likely to consist of people who frequently use the Internet. The population varied in age (18-70 years old), and it was likely that considering themselves or their children, spouses, or parents, they would have a health issue with which they may be inclined to research.

### Data Collection

An Internet-based survey was distributed to each potential respondent using the electronic survey platform *Qualtrix*®. By an e-mail from the South Tippah School District Superintendent of Education's office, each potential participant was invited to participate in the study. The invitation included a link to the survey along with some information about the survey. The potential respondents were informed that the survey

was completely voluntary and that each of their answers would remain confidential. The survey was available for two weeks using the link. One week after the initial e-mail, potential participants were sent a reminder e-mail from the Superintendent's office, and the survey was available for the following week.

Survey Instrument

An Internet-based survey was used by the investigator to collect data from participants. A 17-question survey (Appendix A) was developed by the investigator to observe the public's perspective on using and sharing health information on both general and medical social media sites. Respondents were initially asked if they used any type of social media. With an affirmative response, the participant was asked if he or she uses general social media (such as Facebook, Twitter, and YouTube) followed by a series of questions about his or her general social media use. With a negative response to this question, the participant was referred to attitude questions at the end of the survey. After the general social media questions, the participant was asked if he or she uses medical-based social media. With an affirmative response, the participant answered a series of questions about his or her medical social media use. With a negative response, the participant was sent to the end of the survey to answer a few attitude questions before exiting the survey. The survey included the following categories:

- General demographic questions were included to determine the age, sex, ethnicity, and education of the participant.
- Medical history questions were included to determine medication usage and the illness status of the participant and his or her family members.

- Usage questions were asked to discover which type(s) of social media the participant uses, and these questions were followed by a breakdown of reasons for usage in a 4-point Likert type scale, where 1=not at all and 4=quite often.
- Credibility, benefits, and attitudes of social media sites were measured using a 5-point Likert type scale, where 1=strongly disagree and 5=strongly agree.
    - Thoughts on the credibility of information on social media were adapted from Marketing Scales Handbook.
- Opinions of possible health care provider monitoring on medical social media sites were also reported using a 5-point Likert type scale, where 1=strongly disagree and 5=strongly agree.
- The occurrence of receiving various types of relevant medical information from any social media site were reported using a 4-point linear numeric scale, where 1=not at all and 4=quite often.
- Behavior questions were asked in a multiple choice manner at the end of the survey.

The survey was pre-tested on ten people of various ages and backgrounds to identify wording problems, confusing directions, administration time, and grammar issues. The survey was modified based on the comments from the pre-test. Study methods and procedures were reviewed and approved by the University of Mississippi's Institutional Review Board (IRB).

Data Analysis

Data were exported from *Qualtrix*® to Microsoft Excel (Redmond, WA). Descriptive statistics were calculated to accomplish each objective.

## RESULTS

### Demographics and Medical History

Of available employees of South Tippah School District, 125 responded to the survey. Most respondents were in the 30-49 age range, and 85% of the respondents were female. About 93% of the respondents were white. Over half of the respondents had obtained a professional degree, and 35% held a Bachelor's Degree as their highest degree (Table 1). Only 11.11% of respondents claimed to have a chronic health condition, and 29.41% had an immediate family member with a chronic condition. When asked if the respondent was concerned about obtaining a hereditary disease or passing one to his or her children, 50.42% of respondents clicked the affirmative answer. About 45% of the respondents were on no prescription medications, and about 45% reported taking one or two prescription medications daily (Table 2).

It is important to note that some questions were asked only to those who used certain kinds of social media sites; therefore, the number of respondents to each question was not identical. Additionally, some respondents skipped a few questions, and thus, the N for various questions may differ.

| Demographics | Counts | Percentages |
|---|---|---|
| Age | | |
| 18-29 | 12 | 10.00% |
| 30-39 | 40 | 33.33% |
| 40-49 | 44 | 36.67% |
| 50-59 | 22 | 18.33% |
| 60 and above | 2 | 1.67% |
| Gender | | |
| Male | 18 | 15.00% |
| Female | 102 | 85.00% |
| Ethnicity | | |
| Hispanic or Latino | 0 | 0.00% |
| American Indian or Alaska Native | 0 | 0.00% |
| Asian | 0 | 0.00% |
| Black or African American | 8 | 6.78% |
| Native Hawaiian or Other Pacific Islander | 0 | 0.00% |
| White | 110 | 93.22% |
| Highest Degree Obtained | | |
| High School or GED | 7 | 5.83% |
| Associate Degree | 2 | 1.67% |
| Bachelor's Degree | 42 | 35.00% |
| Master's Degree, Ph.D., or Other Professional Degree | 69 | 57.50% |

**Table 1: Demographics**

| Medical History | Counts | Percentages |
|---|---|---|
| Chronic Health Condition | | |
| Yes | 13 | 11.11% |
| No | 104 | 88.89% |
| Immediate Family Member with Chronic Health Condition | | |
| Yes | 35 | 29.41% |
| No | 84 | 70.59% |
| Concerned about a hereditary disease appearing in his/her own life or passed to children? | | |
| Yes | 60 | 50.42% |
| No | 59 | 49.58% |
| Number of Prescription Medications Taken Daily | | |
| None | 53 | 44.54% |
| 1 | 25 | 21.01% |
| 2 | 28 | 23.53% |
| 3 | 6 | 5.04% |
| 4 or more | 7 | 5.88% |

**Table 2: Medical History**

Social Media Usage

Among the 125 respondents who took the survey, 81.36% (n=118) reported using some type of social media site. Of those who responded affirmatively to that question, 96.84% reported using general social media sites such as Facebook and Twitter. The majority of this group (75.79%) uses Facebook, with YouTube and Twitter being the second and third most popular, respectively. Only 14.46% (n=83) participants reported using medical-based social media (Table 3).

| Social Media Usage | Counts | Percentages |
|---|---|---|
| Any Type of Social Media | | |
| Yes | 96 | 81.36% |
| No | 22 | 18.64% |
| General Social Media (Facebook, Twitter, etc.) | | |
| Yes | 92 | 96.84% |
| No | 3 | 3.16% |
| If yes, which of these sites? | | |
| Facebook | 72 | 75.79% |
| Twitter | 21 | 22.11% |
| YouTube | 43 | 45.26% |
| Other | 9 | 9.47% |
| Instagram | 8 | 8.42% |
| Medical Based Social Media (PatientsLikeMe, etc.) | | |
| Yes | 12 | 14.46% |
| No | 71 | 85.54% |

**Table 3: Social Media Usage**

The survey also helped determine a breakdown of how social media sites are used regarding medical information. For both types of social media, most participants spend more time reading about other people's experiences and opinions on medical issues and treatment than providing their own personal opinions on these topics. It appears that most people are never or rarely using these sites to develop relationships with others with similar medical issues, but in comparing the two types, medical social media users are more likely to use for this purpose (Tables 4 and 5).

| How often do you use general social media for the following: | Not at all | Hardly Ever | Sometimes | Quite often |
|---|---|---|---|---|
| For providing health information | 56.25% | 22.50% | 20.00% | 1.25% |
| For reading health information | 28.75% | 28.75% | 33.75% | 8.75% |
| For developing relationships | 70.00% | 18.75% | 8.75% | 2.50% |

**Table 4: Breakdown of Usage (General Social Media)**

| How often do you use medical social media for the following: | Not at all | Hardly Ever | Sometimes | Quite often |
|---|---|---|---|---|
| For providing health information | 41.67% | 25.00% | 33.33% | 0.00% |
| For reading health information | 8.33% | 8.33% | 83.33% | 0.00% |
| For developing relationships | 58.33% | 16.67% | 25.00% | 0.00% |

**Table 5: Breakdown of Usage (Medical Social Media)**

Attitudes toward Medical Information on Social Media

For both general and medical social media sites, the majority of people had neutral or negative attitudes toward medical information on these sites. The attitude statement that had the most negative response was "I am comfortable sharing personal medical information on a general/medical social media sites" with 72.50% and 66.67% for general and medical sites respectively. For general social media sites, it appears that, although the percentages are small, some people do feel confident receiving and sharing medical information (Table 6). However, for medical social media sites, no user of these sites felt confident receiving or sharing medical information (Table 7).

| Attitudes (General Social Media) | Agree | Neutral | Disagree |
|---|---|---|---|
| Enjoy searching | 23.75% | 33.75% | 42.50% |
| Feel confident receiving | 11.25% | 42.50% | 46.25% |
| Feel comfortable sharing | 7.50% | 20.00% | 72.50% |
| Easy to understand | 17.50% | 61.25% | 21.25% |
| Feel personally empowered after use | 8.75% | 43.75% | 47.50% |

**Table 6: Attitudes (General Social Media)**

| Attitudes (Medical Social Media) | Agree | Neutral | Disagree |
|---|---|---|---|
| Enjoy searching | 33.33% | 50.00% | 16.67% |
| Feel confident receiving | 0.00% | 75.00% | 25.00% |
| Feel comfortable sharing | 0.00% | 33.33% | 66.67% |
| Easy to understand | 33.33% | 50.00% | 16.67% |
| Feel personally empowered after use | 8.33% | 66.67% | 25.00% |

**Table 7: Attitudes (Medical Social Media)**

Credibility of Medical Information on Social Media

When given a few statements concerning the credibility of medical information on social media, most general and medical social media users seem very uncertain. The majority of the responses were neutral in nature. In comparing the two types of social media, it appears that the general social media users doubted credibility much more than medical social media users with disagreeing percentages as high as 50% (Table 8). The medical social media users showed more neutrality than general social media users in every category of credibility with percentages up to 75% (Table 9).

| Credibility (General Social Media) | Agree | Neutral | Disagree |
|---|---|---|---|
| Credible | 6.25% | 43.75% | 50.00% |
| Unexaggerated | 2.50% | 47.50% | 50.00% |
| Believable | 13.75% | 61.25% | 25.00% |
| Honest | 13.75% | 58.75% | 27.50% |

**Table 8: Credibility (General Social Media)**

| Credibility (Medical Social Media) | Agree | Neutral | Disagree |
|---|---|---|---|
| Credible | 8.33% | 74.67% | 16.70% |
| Unexaggerated | 8.33% | 66.67% | 25.00% |
| Believable | 16.67% | 66.66% | 16.67% |
| Honest | 8.33% | 75.00% | 16.67% |

**Table 9: Credibility (Medical Social Media)**

The survey also addressed the amount of relevant medical information received from either type of social media site. Of the three types of medical information given, the most relevant information obtained is about the user's or a family member's medical condition. About half of social media users report never receiving any relevant information from these sites about currently prescribed drugs or new drugs (Table 10).

| How often do you get any relevant information about each of the following items from general or medical social media sites? | Not at all | Hardly ever | Sometimes | Quite often |
|---|---|---|---|---|
| Your or a family member's medical condition | 36.71% | 25.32% | 36.70% | 1.27% |
| Your or a family member's currently prescribed drugs | 50.63% | 17.72% | 31.65% | 0.00% |
| New drugs not currently used by you or a family member | 55.70% | 13.92% | 29.11% | 0.00% |

**Table 10: Relevant Medical Information Obtained**

Benefits of Medical Information on Social Media

Perceived benefits of medical information on social media differed between general and medical social media users. Medical social media users mostly think that medical information on these sites is beneficial, or they are unsure about the benefits. A majority of both general and medical social media users agreed that social support is a reason for using these sites. When comparing the responses to a statement about users becoming more knowledgeable by using social media sites for medical purposes, a majority of general social media users disagreed that these sites are increasing the knowledge of the users (Table 11). However, a majority of the medical social media users were neutral on this topic. In fact, the same amount of participants agreed and disagreed (Table 12).

| Benefits (General Social Media) | Agree | Neutral | Disagree |
|---|---|---|---|
| More knowledgeable | 8.75% | 37.50% | 53.75% |
| Increased social support | 57.50% | 33.75% | 8.75% |
| Better health condition management | 23.75% | 40.00% | 36.25% |

**Table 11: Benefits (General Social Media)**

| Benefits (Medical Social Media) | Agree | Neutral | Disagree |
|---|---|---|---|
| More knowledgeable | 16.67% | 66.66% | 16.67% |
| Increased social support | 58.33% | 41.67% | 0.00% |
| Better health condition management | 25.00% | 58.33% | 16.67% |

**Table 12: Benefits (Medical Social Media)**

Need for Monitoring Medical Social Media Sites

Questions about the perceived need for monitoring medical social media sites provided the most consistent results for individual questions within a category. Although some participants held a neutral opinion on this subject, no participant disagreed with the statements that monitoring would be helpful, that they would support monitoring, and that they would use this type of social media more often if it was monitored (Table 13).

| Opinions on Potential Monitoring | Agree | Neutral | Disagree |
|---|---|---|---|
| It would be helpful if health information was reviewed for accuracy by healthcare providers. | 63.64 | 36.36% | 0.00% |
| I would support health information being monitored by health care providers. | 66.67 | 33.33% | 0.00% |
| I would use more often if it were monitored by HCPs. | 66.67 | 33.33% | 0.00% |

**Table 13: Opinions on Potential Monitoring**

Resulting Behaviors

After looking at the four main objectives, it is important to look at the effect that this information has on behaviors of social media users. 63.29% of participants in this study claim to have searched for more information on the Internet about a medication based on information found on a social media site. It appears that this is the most common medication behavior following the discovery of new information on a social media site. However, only 6.33% of participants claim to have changed a dosage or otherwise altered a medication based on information found on social media sites. This is the least common action seen in participants of this study (Table 14).

| With respect to medications, have you done any of the following based on info from general or medical social media sites? | Percentage of Participants |
|---|---|
| Searched for more info on the web about the medication | 63.29% |
| Requested a new medication from doctor | 10.13% |
| Taken medications as directed | 24.05% |
| Changed dose or altered medications | 6.33% |
| Stopped taking a medication | 17.72% |

**Table 14: Resulting Behaviors**

## DISCUSSION

It is obvious at the current time that the general public is frequently using social media sites. General social media seems to be used much more than medical social media sites. This could be because people are unaware that such specialized sites exist or do not feel as if they have a serious chronic condition that warrants joining a medical social media site. People seem less likely to consider themselves as having a chronic disease, but it is important to note that these people may have various definitions of the phrase "chronic disease." The majority of the people in the study claim to be taking no medications daily. Although most participants do not consider themselves to have any chronic illnesses, they seem very concerned about the appearance of a hereditary disease in their lives and/or passing one of these diseases down to their children.

A majority of general social media users never use these sites for providing information about personal experiences and opinions on medical issues or treatment. However, a few participants claim to provide and receive information quite often. When looking at medical social media usage, there is a large percentage of participants who report sometimes reading about others' medical information. As a pharmacist, it is critical to know that, although most people are not sharing information on these sites, they are indeed reading other people's information. When a patient comes into a physician's office or a pharmacy, the patient is coming in with knowledge gained from other people

on social media sites, without the knowledge of whether or not it is reliable information. Also, it seems that the most relevant health information received from social media is about the medical condition of the user, or one of the user's family members, rather than about new drugs or drugs that are currently being taken. Pharmacists should also take this information into consideration because it appears that patients are coming in with doubts about information received online about drugs. This creates a vast gap that can be filled by pharmacists in persuading patients who are social media users to believe the "drug expert" rather than the general public online.

It is also clear that people are very skeptical about the credibility of any health information shared on general social media sites such as Facebook, which is the most common social media site used by those in the study. Very few people agree with the fact that this health information is credible, unexaggerated, believable, and honest. However, for the latter two characteristics, a majority of the participants report as having a neutral stance. On medical social media, the neutral category held the majority of participants for each of the subgroups. From an overall perspective, it seems that the general public does not know whether or not medical information on social media can be trusted.

Across both types of social media, it is clear that the perceived main benefit that can be received through these sites is gained social support. Many people are using these sites just to feel included and to know that they are not alone in living with certain chronic conditions. The users may not think they are becoming more knowledgeable and learning to manage their health conditions better, but they admit that community can be found within these sites regardless.

Attitudes about medical information on general social media vary, but most people are neutral or have negative views toward this information. On all subcategories except "feel comfortable sharing," users of medical social media have very neutral attitudes. For both types of social media, users feel least comfortable sharing information. This information tells pharmacists that patients are much less likely to be sharing information than receiving information from the Internet.

It is also important to look at how social media sites have affected patients' medication habits. Over half of participants say that they have, in fact, searched for more information about a medication because of something they have seen on general or medical social media sites. It is also noteworthy to mention that 24% of patients have been motivated to take their medications as directed because of things they have seen on social media sites. This shows that these sites also have the potential to have a positive impact on patient adherence. It is also good news to find that patients have been least likely to change the dose or otherwise alter a current medication solely based off of social media information, as this could be a very dangerous behavior to result from social media use.

Knowing all of this information about patients, it is not surprising that all medical social media users support the idea of monitoring by a health care provider on these sites. The participants report that, if monitoring is implemented, they would feel less skeptical about the medical information provided and would use these sites more often.

In order for pharmacists to make a difference in the realm of social media, they should consider creating their own type of social media for their particular pharmacy.

People are very interested in having a medical social media site that is monitored by educated health care providers, and this type of site would allow the people this luxury. Patients are more likely to ask personal questions anonymously via social media sites than in person surrounded by people who may seem judgmental or far too educated to understand. Pharmacy social media sites could break down barriers by allowing patients to ask important life-altering questions without feeling afraid or embarrassed. Patients would also be much more open to and much less skeptical of receiving advice from an actual health care practitioner than just from a person who has experienced a disease or medication.

Even if a pharmacist does not have the resources or time to set up a social media site at this time, he or she can still make an impact on patient's lives with the knowledge obtained from this study. All pharmacists should also make an effort to hear out a patient's concerns about things they have read on social media. Pharmacists have the power to persuade a patient to convert any uncertain thoughts into accurate advice and information. As one of the most trusted professions in the country, it is likely that patients will listen to and implement a pharmacist's advice over a peer's advice through social media if only they have the opportunity to speak to a pharmacist.

## Limitations

The results of this study should be examined and interpreted cautiously because of several limitations involved in the study. External validity of the findings is one such limitation. It is unknown whether a different group of Internet users has the same

perception toward medical information on social media sites. This group of participants had much in common demographically, and different demographic and medical history characteristics could result in different study results. Additionally, there is a large difference seen in the amount of participants who answered the general social media questions versus the medical social media questions. It could be useful to find a population of people who are more likely to use medical social media sites.

## CONCLUSION

Social media has become a large part of our society today, and it is clear that medical information has worked its way into these sites. Each patient that comes into a pharmacy is very likely to have some type of medical knowledge obtained from a social media site. This study revealed that social media users are, in fact, reading health information on social media sites, but they are mostly skeptical of the information they receive. They are uncertain about the credibility and benefits of the information and seem to be in favor of online monitoring by health care providers. With the growth of social media, it is important for pharmacists to help patients decipher between credible and non-credible information. Because medical social media users approve of the idea of monitoring of such sites, pharmacists should also consider creating monitored sites for their patients. Above all, pharmacists should keep in mind the information obtained in this study in order to fulfill their duty of obtaining optimal outcomes for each and every patient with which they come into contact.

Bibliography

Crocco, Anthony G., Miguel Villasis-Keever, and Alejandro R. Jadad. "Analysis of cases of harm associated with use of health information on the internet." *JAMA: the journal of the American Medical Association* 287.21 (2002): 2869-2871.

Daugherty, Terry, Matthew S. Eastin, and Laura Bright. "Exploring consumer motivations for creating user-generated content." *Journal of Interactive Advertising* 8.2 (2008): 1-24.

Ellison, Nicole B. "Social network sites: Definition, history, and scholarship." *Journal of Computer-Mediated Communication* 13.1 (2007): 210-230.

Frost, Jeana H., and Michael P. Massagli. "Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data." *Journal of Medical Internet Research* 10.3 (2008).

"HealthBoards.com FAQ (Frequently Asked Questions)." *HealthBoards*. N.p., n.d. Web. 02 Mar. 2013. <http://www.healthboards.com/boards/faq.php?faq=faq_hb>.

Kamal, Thapar, Newt Gingrich. "Medicine in the Facebook age." *The Atlanta journal-constitution (2001)* 26 Dec 2010: A23. *Atlanta Newspapers*. 02 Mar 2013.

O'Brien, Clodagh. "The emergence of the social media empowered consumer." *Irish Marketing Review* 21.1/2 (2011): 32-40.

Park, Alice. "Web Mds." *Time* 180.6 (2012): 16. *Vocational and Career Collection*. Web. 31 Mar. 2013.

Risk, Ahmad, and Joan Dzenowagis. "Review of internet health information quality initiatives." *Journal of medical Internet research* 3.4 (2001).

"Site Info." *Alexa - The Web Information Company*. Amazon.com, n.d. Web. 02 Mar. 2013. <http://www.alexa.com/siteinfo/alexa.com>.

Thackeray, Rosemary, Benjamin T. Crookston, and Joshua H. West. "Correlates of health-related social media use among adults." *Journal of medical Internet research* 15.1 (2013).

"User Agreement." *PatientsLikeMe*. N.p., n.d. Web. 02 Mar. 2013. <http://www.patientslikeme.com/about/user_agreement>.

Wicks, Paul, et al. "Sharing health data for better outcomes on PatientsLikeMe." *Journal of medical Internet research* 12.2 (2010).

# APPENDICES

# APPENDIX A: E-MAIL COVER LETTER

February 3, 2014

Dear Participant:

My name is Brea Rich, and I graduated from Ripley High School in 2010. I am now a senior and first-year pharmacy school student at the University of Mississippi. As my senior thesis for the Sally McDonnell Barksdale Honors College, I am examining the general public's perception on using and sharing health information on social media sites. Because you are employed adults at South Tippah School District, I am inviting you to participate in this research study by completing the attached survey.

The following survey will require approximately 5-10 minutes to complete. There is no compensation for responding nor is there any known risk. In order to ensure that all information will remain anonymous, please do not include your name. If you choose to participate in this project, please answer all questions as honestly as possible. Participation is strictly voluntary and you may refuse to participate at any time.

Thank you so much for taking the time to assist me in my educational endeavors. The data collected will provide useful information regarding perceptions of health information on social media sites. Clicking on the link below and completing the survey will indicate your willingness to participate in this study. If you have questions, please contact me at the e-mail address or number listed below.

*If you have any concerns or need additional information about how this study is being conducted, please contact the University of Mississippi IRB at 662-915-7482.*

<LINK>

Sincerely,

Brea Rich

bhrich@go.olemiss.edu

Donna West-Strum

dswest@olemiss.edu

662-915-1071

# APPENDIX B: SURVEY

Survey

Perceptions of Medical Information on Social Media

Q1 What is your age in years?

- ❍ 18-29 (1)
- ❍ 30-39 (2)
- ❍ 40-49 (3)
- ❍ 50-59 (4)
- ❍ 60 and above (5)

Q2 What is your gender?

- ❍ Male (1)
- ❍ Female (2)

Q3 What is your ethnicity?

- ❍ Hispanic or Latino (1)
- ❍ American Indian or Alaska Native (2)
- ❍ Asian (3)
- ❍ Black or African American (4)
- ❍ Native Hawaiian or Other Pacific Islander (5)
- ❍ White (6)

Q4 What is your highest degree obtained?

- ❍ High School or GED (1)
- ❍ Associate Degree (2)
- ❍ Bachelor's Degree (3)
- ❍ Master's Degree, Ph.D., or Other Professional Degree (4)

Q5 Do you have a chronic health condition?

- ❍ Yes (1)
- ❍ No (2)

Q6 Does anyone in your immediate family have a chronic health condition?

- ❍ Yes (1)
- ❍ No (2)

Q7 Is there a hereditary disease that you are concerned about appearing later in your life or being passed on to your children?

- ❍ Yes (1)
- ❍ No (2)

Q8 How many prescription medications do you take on average each day?

- ❍ None (1)
- ❍ 1 (2)
- ❍ 2 (3)
- ❍ 3 (4)
- ❍ 4 or more (5)

Q21 Do you ever use general social media (such as Facebook, Twitter, and YouTube) or medical based social media (such as PatientsLikeMe or HealthBoards.com)?

- ❍ Yes (1)
- ❍ No (2)

If No Is Selected, Then Skip To End of Survey

Q9 Do you use general social media (such as Facebook, Twitter, and YouTube)?

- ❍ Yes (1)
- ❍ No (2)

If No Is Selected, Then Skip To Have you ever used a medical based so...

Q10 If so, which of these sites do you use?

- ❑ Facebook (1)
- ❑ Twitter (2)
- ❑ YouTube (3)
- ❑ Other (4) _____

Q11 When using general social media (Facebook, Twitter, YouTube, etc.), how often do you use them for the following items?

| | Not at all (1) | Hardly ever (2) | Sometimes (3) | Quite often (4) |
|---|---|---|---|---|
| For providing your personal experiences and opinions on medical issues or treatment (1) | ❍ | ❍ | ❍ | ❍ |
| For reading other people's experiences and opinions on medical issues and treatment (2) | ❍ | ❍ | ❍ | ❍ |
| For developing relationships with others with similar medical issues (3) | ❍ | ❍ | ❍ | ❍ |

Q12 Please indicate your level of agreement with each of the following statements. "General Social Media" refers to sites like Facebook, Twitter, and YouTube.

| | Strongly Disagree (1) | Disagree (2) | Neither Agree nor Disagree (3) | Agree (4) | Strongly Agree (5) |
|---|---|---|---|---|---|
| The medical information on general social media sites is credible. (1) | ❍ | ❍ | ❍ | ❍ | ❍ |
| The medical information on general social media sites is exaggerated. (2) | ❍ | ❍ | ❍ | ❍ | ❍ |
| The medical information on general social media sites is unbelievable. (3) | ❍ | ❍ | ❍ | ❍ | ❍ |
| The medical information on general social media sites is honest. (4) | ❍ | ❍ | ❍ | ❍ | ❍ |
| People using general social media sites for medical information are more knowledgeable. (5) | ❍ | ❍ | ❍ | ❍ | ❍ |
| People are using general social media sites for social support with medical issues. (6) | ❍ | ❍ | ❍ | ❍ | ❍ |
| People using general social media sites for medical purposes are | ❍ | ❍ | ❍ | ❍ | ❍ |

| | | | | | |
|---|---|---|---|---|---|
| able to manage their health conditions better. (7) | | | | | |
| I enjoy searching general social media sites for medical information. (8) | ❍ | ❍ | ❍ | ❍ | ❍ |
| I feel confident about receiving medical information from my peers on general social media sites. (9) | ❍ | ❍ | ❍ | ❍ | ❍ |
| I am comfortable sharing personal medical information via a general social media site. (10) | ❍ | ❍ | ❍ | ❍ | ❍ |
| I think the health information on general social media sites is easy to understand. (11) | ❍ | ❍ | ❍ | ❍ | ❍ |
| I feel personally empowered after using a general social media to find health information. (12) | ❍ | ❍ | ❍ | ❍ | ❍ |

Q13 Have you ever used a medical based social media like PatientsLikeMe.com or HealthBoards.com (or any site that allows users to share/receive medical information)?

❍ Yes (1)

❍ No (2)

If No Is Selected, Then Skip To How often do you get any relevant inf...

Q14 When using medical based social media sites, how often do you use them for the following items? "Medical based social media" refers to sites like PatientsLikeMe.com or HealthBoards.com (or any site that allows users to share/receive medical information).

| | Not at all (1) | Hardly ever (2) | Sometimes (3) | Quite often (4) |
|---|---|---|---|---|
| For providing your personal experiences and opinions on medical issues or treatment (1) | ❍ | ❍ | ❍ | ❍ |
| For reading other people's experiences and opinions on medical issues and treatment (2) | ❍ | ❍ | ❍ | ❍ |
| For developing relationships with others with similar medical issues (3) | ❍ | ❍ | ❍ | ❍ |

Q15 Please indicate your level of agreement with each of the following statements. "Medical based social media" refers to sites like PatientsLikeMe.com or HealthBoards.com (or any site that allows users to share/receive medical information).

| | Strongly Disagree (1) | Disagree (2) | Neither Agree nor Disagree (3) | Agree (4) | Strongly Agree (5) |
|---|---|---|---|---|---|
| The medical information on medical social media sites is credible. (1) | ❍ | ❍ | ❍ | ❍ | ❍ |
| The medical information on medical social media sites is exaggerated. (2) | ❍ | ❍ | ❍ | ❍ | ❍ |
| The medical information on medical social media sites is unbelievable. (3) | ❍ | ❍ | ❍ | ❍ | ❍ |
| The medical information on medical social media sites is honest. (4) | ❍ | ❍ | ❍ | ❍ | ❍ |
| People using medical social media sites for medical information are more knowledgeable. (5) | ❍ | ❍ | ❍ | ❍ | ❍ |
| People are using medical social media sites for social support with medical issues. (6) | ❍ | ❍ | ❍ | ❍ | ❍ |
| People using medical social media sites for | ❍ | ❍ | ❍ | ❍ | ❍ |

| | | | | | |
|---|---|---|---|---|---|
| medical purposes are able to manage their health conditions better. (7) | | | | | |
| I enjoy searching medical social media sites for medical information. (8) | ❍ | ❍ | ❍ | ❍ | ❍ |
| I feel confident about receiving medical information from my peers on medical social media sites. (9) | ❍ | ❍ | ❍ | ❍ | ❍ |
| I am comfortable sharing personal medical information on a medical social media site. (10) | ❍ | ❍ | ❍ | ❍ | ❍ |
| I think the information on medical social media sites is easy to understand. (11) | ❍ | ❍ | ❍ | ❍ | ❍ |
| I feel personally empowered after using a medical social media to find health information. (12) | ❍ | ❍ | ❍ | ❍ | ❍ |
| It would be helpful if | ❍ | ❍ | ❍ | ❍ | ❍ |

| | | | | | |
|---|---|---|---|---|---|
| health information on medical social media sites was reviewed for accuracy by healthcare providers. (13) | | | | | |
| I would support health information on medical social media sites being monitored by health care providers. (14) | ❍ | ❍ | ❍ | ❍ | ❍ |
| I would use medical social media sites more often if they were monitored by health care providers. (15) | ❍ | ❍ | ❍ | ❍ | ❍ |

Q16 How often do you get any relevant information about each of the following items from general or medical social media sites?

| | Not at all (1) | Hardly ever (2) | Sometimes (3) | Quite often (4) |
|---|---|---|---|---|
| You or your family member's medical condition (1) | ❍ | ❍ | ❍ | ❍ |
| You or your family member's currently prescribed drugs (2) | ❍ | ❍ | ❍ | ❍ |
| New drugs that you or a family member are not currently using (3) | ❍ | ❍ | ❍ | ❍ |

Q17 With respect to medications, have you done any of the following based on information from general or medical social media sites? Check all that apply.

- ❑ Searched for more information on the web about the medication (1)
- ❑ Requested a new medication from my doctor (2)
- ❑ Taken my medications as directed (3)
- ❑ Changed dose or altered medications (4)
- ❑ Stopped taking a medication (5)